

# Sleep Problems in Relation to Autism Severity, Problematic Behaviour and Parental Distress in Children with Low Functioning Autism

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## Abstract

One of the most burdensome and profound complaints among parents of children with autism is disrupted sleep, with more than 40-80% of the children experiencing sleep problems, compared with 25-40% in typically developing children. The consequence of disrupted sleep is potentially serious; it may exacerbate core ASD symptoms. Research is limited on sleep and its relation to behavioural problems and parental distress in low functioning autism. The main aim of the current study is to assess sleep problems in relation to severity of autism, day time problem behavior and parental distress in children with low functioning autism. A descriptive cross sectional design was adopted for the study among 40 children aged between 6-16 years of age, recruited from selected special schools and autism centres in Kerala. Sleep problems, autism severity, problematic behavior and parental distress were assessed using the Children's Sleep Habit Questionnaire (CSHQ), the Social Responsive Scale (SRS), the Disruptive Behaviour Disorder Rating Scale, and the Parenting Stress Index respectively. Prevalence of sleep problems were more among children with low functioning autism. All of the children in the study met the cut off score of sleep problems in the CSHQ. However, sleep problems were not correlated with severity of autism, problematic behaviour and parental distress. Findings showed that autism severity is

related to parental stress ( $p=0.046$ ) and problem behaviour ( $p<0.01$ ) in children with autism. It was also observed that problematic behaviour in children is correlated with parental stress ( $p=0.019$ ). Study results emphasize the need for implementing interventions to reduce sleep problems, problematic behaviours and parental distress

**Keywords:** Low Functioning Autism, Sleep Problems, Problem Behaviours, Parental Distress, Autism Severity

## Introduction

Sleep plays an integral role in the healthy development of children (Dahl, 1996). It serves multiple functions which include energy conservation, brain growth, memory consolidation and cognition (Stores & Wiggs, 1998). School aged children have greater sleep needs when compared to adolescents and adults and they typically require 10-11 hours of sleep at night (Meltzer & Mindell, 2006). Today an average child is not getting the recommended amount of sleep which results in consequences in daily behavior. In healthy children, sleep problems negatively impact day to day life, socio-emotional, behavioural (Pesonen, Raikonen, Paavonen, Heinonen, Komsj, Lahti, 2010), academic, occupational, functioning, (Dewald, Meijer, Oort, Kerkhof, & Bogels, 2010), family cohesion (Bell & Belsky, 2008; Simard,

Nielsen, Tremblay, Boivin, & Montplaisir, 2008) and neuro psychological abilities (Mary, Harvey, & William, 1981). Maladaptive sleep patterns are also evidenced as a detriment to daytime behavior and cognition in typically developing children (Allen et al., 2003). Disturbed sleep is associated with diminished performance in typically developing children's functioning in areas such as memory, vigilance, and affect (Kheirandish & Gozal, 2006; Sadeh, Gruber, & Raviv, 2002). Significant cognitive delays in higher mental functions, such as verbal fluency and abstract thinking, are displayed in typically developing children following just one night of sleep deprivation (Randazzo, Meuhlbach, Schweitzer, & Walsh, 1998). Furthermore, children's sleep-disordered breathing is suggested to be associated with higher rates of inattention, hyperactivity, and aggression (Chervin et al., 2002; Gottlieb, Vezina, & Chase, 2003). Children with autism present with difficulties in social interaction and communication, and exhibit restricted and repetitive stereotyped behaviors and interests (American Psychiatric Association, 2006). The characteristics associated with autism have been found to be especially challenging (Hastings, 2002; Perry, 2005), with parents of children with autism reporting higher levels of stress than parents of children with Down syndrome, other psychiatric difficulties, or developmental disabilities (Duarte, Bordin, Yazigi, & Mooney, 2005; Eisenhower, Baker, & Blacher, 2005; Tomanik, Harris, & Hawkins, 2004). One of the most burdensome and profound complaints among parents of children with autism is disrupted sleep, with more than 40-80% of these children experiencing sleep problems, compared with 25-40% in typically developing children. (Meltzer & Mindell, 2006; Reynolds & Malow, 2011). The consequences of disrupted sleep are potentially serious; it may exacerbate core ASD symptoms (Park et al., 2012; Tudor, Hoffman, &

Sweeney, 2012). Sleep problems exhibited by children with autism may magnify the problems of parental stress again. Research is limited on sleep in relation to behavioural problems and parental distress in low functioning autism. Sleep problems are also associated with more challenging behaviours of children with autism during the day, and have an impact on the ability to regulate emotion. (Henderson, Barry, Bader & Jordan, 2011; Goldman et al., 2011)

Recent evidence suggests that sleep problems, reported by parents of children with autism, are related to the children's daytime symptomatology (Hoffman et al., 2005; Schreck, Mulick, & Smith, 2004) However, others have suggested there are no direct links between children's sleep problems and the severity of their autism (Wiggs & Stores, 2004). To date, the relationship between sleep difficulties associated with autism and parental stress has received little empirical attention. Children's sleep problems have been related to maternal stress in children with other developmental disabilities (Honomichl, Goodlin-Jones, Burnham, Gaylor, & Anders, 2002). For example, a study of children with Fragile X syndrome, (Richdale, 2003) reported that children's sleep problems were related to their behavioral difficulties and to parental stress. (Richdale, Francis, Gavidia-Payne, & Cotton, 2000) found that parents of children with an intellectual disability reported that children's sleep problems were related to their behavior problems and to parenting hassles. Moreover, (Wiggs & Stores, 2001) indicated that treating sleep problems in children with severe intellectual disabilities led to decreases in maternal stress. Children's sleep problems may contribute to stress in parents of children with autism, but other factors could be equal contributors. For example, parents' stress is probably affected by their children's symptoms, as well as by their own sleep difficulties (Richdale, 2003; Richdale, et al., 2000;

Wiggs & Stores, 2001) suggested that, when children have sleep problems the whole family may experience ensuing disturbances. Patzold, Richdale & Tonge (1998), using sleep diaries completed by parents, suggested that sleep problems of children with autism or Asperger's disorder disturbed parents' sleep, thereby increasing their stress. In a study (Cotton & Richdale, 2006), parents provided descriptions of the sleep problems of their children with intellectual disabilities (including a sample of children with autism), indicating that both their child's behaviour and the family's well-being were adversely affected by the child's sleep problems. The present investigation examined the relationship among children's sleep problems and parental stress, problem behaviours and autism severity.

## Objectives

The main aim of the study was to assess sleep problems in relation to severity of autism, day time problem behavior and parental distress in children with low functioning autism.

## Methods

### Study Design

A descriptive cross sectional design was adopted for the study to assess sleep problems in children with autism and to find its relationship to autism severity, problem behavior and parental stress.

### Participants

Subjects included 40 children aged between 6-16 years of age (mean age=13.18 SD= 2.9), recruited from selected special schools and autism centers in Kerala. The study was conducted in June 2017. All of the children in the school who met the inclusion and exclusion criteria of the study were recruited for the study using the convenience sampling method. Parents of the selected children completed the tools:

Children's Sleep Habit Questionnaire (CSHQ), Social Responsive Scale (SRS), The Disruptive Behaviour Disorder Rating Scale, and the Parenting Stress Index.

### A) Children

#### *Inclusion criteria for children were*

- Children with low functioning autism as per DSM V, as diagnosed by a Psychiatrist, which is needed for admission to an autism centre.
- Age 6-16 years
- Those children whose parents were available during the period of study

#### *Exclusion Criteria*

- Presence of active symptoms of comorbid psychiatric illness

### B) Parent

#### *Inclusion Criteria*

- Parents (either mother or father) who were willing to participate.
- Parents staying with the child for at least one year prior, and were the primary care givers of the child.

#### *Exclusion Criteria*

- Parents who couldn't speak Malayalam/English

### *Instruments*

**1. Baseline data** Information collected from the parent detailing age, gender, domicile, type of family, education of parents, and parental marital status.

**2. Children's Sleep Habit Questionnaire (CSHQ) (Owens et al.)**

CSHQ is a retrospective, 45 item parent questionnaire to examine sleep behavior in children. It includes items relating to a number of key sleep domains that encompass the major presenting clinical sleep complaints in this age group; bed time behaviour and sleep onset, sleep duration, anxiety around sleep, behaviour occurring during sleep, and night waking, sleep disordered breathing, parasomnias, and morning waking/day time sleepiness. Parents were

requested to recall sleep behaviours occurring over a “typical” week. Items **were rated on a three point scale**, “usually” if the sleep behavior occurred five to seven times/week, “sometimes” for two to four times/week, and “rarely” for zero to one time/week. Some items were reversed in order to consistently make a higher score indicative of more disturbed sleep. The internal consistency of the entire CSHQ was 0.68 for the community sample and 0.78 for the clinical sample: alpha coefficients for the various subscales of the CSHQ ranged from 0.36 (Parasomnias) to 0.70 (Bedtime Resistance) for the community sample, and from 0.56 (Parasomnias) to 0.93 (Sleep-Disordered Breathing) for the sleep clinic group. Test-retest reliability was acceptable (range 0.62 to 0.79). The correlations for the subscales ranged from 0.62 to 0.79.

### **3. Social Responsive Scale (SRS) (Roeyer et al., 2011)**

Autism symptom severity was measured by the Social Responsive Scale. It is a 65 item scale designed to examine autistic traits, and consists of five scales; social awareness, social cognition, social communication, social motivation and autistic mannerisms. A higher score indicates more autistic traits. This measure has been shown to compare well with the Autism Diagnostic Interview-Revised (ADI-R) in the assessment of ASDs ( $r=0.64$ , Constantino et al., 2003) and good reliability has been reported. (Cronbach's alpha =0.94, Constantino and Guberr, 2005, Roeyr's et al., 2011).

### **4. The Disruptive Behaviour Disorder Rating Scale (Pelham et al., 1992)**

This scale is a 41 item parent questionnaire developed to assess problem behaviors in children. It consists of symptom description of four disorders. ADHD inattentive subtype (Attention), ADHD hyperactive/impulsive subtype (Hyper activity), Oppositional defiant disorder (ODD) and conduct disorder (CD). Each statement is rated

on how well it describes the child's behavior in a 4 point scale ranging from 0 (not at all) to 3 (very well). A higher score indicates more symptoms of externalizing problem behaviors. Psychometric properties of the DBD have been reported for each of the sub scales: Attention (Cronbach's alpha =.92), Hyper activity (Cronbach's alpha =.90), ODD (Cronbach's alpha =.90), and CD (Cronbach's alpha =.92, Oosterlaan, et al., 2008, Pelham meal, 1992).

### **5. Parenting stress index (PSI, Abidin, 1983)**

An 11 item Parenting Distress sub scale was used to assess parenting stress. These items have an internal consistency of 0.85, representing a short index for parenting stress. Items capture four domains of competence (6), attachment (1) depression (3) and health (1). Answers ranged on a 5 point Likert scale ranging from 1 (totally disagree) to 5 (totally agree), resulting in a higher total stress score, representing more stress.

#### **Procedures**

After getting written informed consent from parents, sleep problems, autism severity, problematic behavior and parental distress were assessed using the Children's Sleep Habit Questionnaire (CSHQ), the Social Responsive Scale (SRS), the Disruptive Behaviour Disorder Rating Scale, and the Parenting Stress Index respectively, which were translated into the local language.

#### **Ethical considerations:**

- a) Written informed consent was obtained from the child's parents
- b) Parents involved in the study were in formed clearly of the purpose and objectives of the same.
- c) Parents selected for the study were assured of confidentiality of information provided to the researcher.

## **Results**

Analysis of the data was done using SPSS. The significance level was taken as <0.05. Mean age of the sample was  $13.1 \pm 2.9$ .

**Table 1 :** Demographic variables (N=40)

| variable                 | category  | N (%)      |
|--------------------------|-----------|------------|
| Gender                   | Male      | 27 (67.5%) |
|                          | Female    | 13 (32.5%) |
| Domicile                 | Urban     | 36 (90.0%) |
|                          | Rural     | 4 (10.0%)  |
| Type of family           | Nuclear   | 33 (82.5%) |
|                          | Joint     | 7 (17.5%)  |
| Parental marital status. | Married   | 34 (85.0%) |
|                          | Separated | 3 (7.50%)  |
|                          | Divorced  | 2 (5.0%)   |
|                          | Widower   | 1 (2.5%)   |

Table 1 shows that, out of the 40 samples, 27 (67.5%) were boys and the rest (32.5%) were girls. The majority (90%) of participants were from urban areas and a majority (82.5%) belonged to a nuclear family.

**Table 2 :** Sleep problems in children with low functioning autism

| Variable              | Minimum | Maximum | Mean ± SD   |
|-----------------------|---------|---------|-------------|
| Sleep problems (CSHQ) | 1       | 74      | 27.5 ± 18.4 |

Sleep problems were assessed in the following domains: bed time resistance, and sleep onset, sleep duration, anxiety around sleep, behaviour occurring during sleep, and night waking, sleep disordered breathing, parasomnias, and morning waking/day time sleepiness. All of the children participating in the study, met the criteria for sleep problems (cut off point 41) with a mean score of 27.5 and SD 18.4. (Table2)

The majority (51%) of children averaged 8–9 hours of nightly sleep, with nearly equal numbers of children averaging 6–7 hours nightly (20%) or 10–11 hours nightly (18%). Approximately 10% of children received only 4–5 hours nightly and only 1 % had more than 11 hours of sleep. Parent responses to time of waking revealed that 21% of children awoke before 06:00 hours, 47% between 06:00 and 07:00 hours, and 30% after 07:00 hours.

**Table 3 :** Description of sleep problems in different domains N=40

| Domains of sleep problems  | Minimum | Maximum | Mean ± SD  |
|----------------------------|---------|---------|------------|
| Bed time resistance        | 8       | 18      | 13.1 ± 2.6 |
| Sleep onset delay          | 1       | 3       | 2.1 ± 0.7  |
| Sleep duration             | 4       | 9       | 6.6 ± 1.1  |
| Sleep anxiety              | 3       | 16      | 8.3 ± 3.1  |
| Night waking               | 3       | 9       | 5.7 ± 1.8  |
| Parasomnias                | 7       | 21      | 12.3 ± 3.8 |
| Sleep disordered breathing | 3       | 12      | 5.1 ± 2.2  |
| Day time sleepiness        | 10      | 24      | 16.4 ± 4.4 |

Most frequently reported problems were with bed time resistance and sleep duration, followed by sleep anxiety, sleep onset delay and day time sleepiness. Least reported problems were disordered breathing, parasomnias, and night waking.

**Table 4 :** Description of autism severity, problem behaviours and parental stress

| Variable                  | Minimum | Maximum | Mean ± SD    |
|---------------------------|---------|---------|--------------|
| Autism severity (SRS)     | 65      | 174     | 124.5 ± 26.7 |
| Parental stress (PSI)     | 22      | 55      | 38.9 ± 8.7   |
| Problem behaviour (DBDRS) | 46      | 97      | 69.3 ± 13.8  |

Table 3 shows that autism severity in children measured by SRS revealed a score of 124.5 with a SD of 26.7. Parental stress in the sample was 38.9 ± 8.7, and problem behaviour in children with autism was 69.3 ± 13.8.

Relationship among Sleep problems (CSHQ), autism severity (SRS), problematic behavior (DBDRS) and parental distress (PSI) Shows in table 5

**Table 5** : Relationship between different selected Variables

| Correlation  | r       | p       |
|--------------|---------|---------|
| CSHQ & SRS   | 0.013   | 0.938   |
| CSHQ & PSI   | 0.002   | 0.989   |
| CSHQ & DBDRS | 0.048   | 0.768   |
| SRS & PSI    | 0.317*  | 0.046*  |
| SRS & DBDRS  | 0.536** | <0.01** |
| DBDRS & PSI  | 0.369*  | 0.019*  |

\*\* Correlation is significant at the 0.01 level (2-tailed)

\* Correlation is significant at the 0.05 level (2-tailed)

Normality of variables were checked by the Shapiro Wilk normality test and found that data followed normal distribution. Hence, Pearson correlations were performed on scores for the CSHQ and SRS, to examine relationships between sleep problems and autism severity, and showed that there is no statistically significant relationship between them ( $p=0.938$ ), and also that sleep problems are not related to parental stress and problematic behaviours in children ( $p>0.05$ ). Autism severity showed statistically significant correlation with parental stress ( $p=0.046$ ) and problematic behaviours ( $p<0.01$ ). Parental stress also showed in relation to problematic behaviours in children ( $p=0.019$ )

## Discussion

Study findings revealed that children with ASD present with sleep related problems. All children with autism participating in the current study, were described as having moderate to severe sleep problems. The most frequently reported problems were bed time resistance and sleep duration, followed by sleep anxiety, sleep onset delay and day time sleepiness. Least reported problems were disordered breathing, parasomnias, and night waking. Parasomnias, such as sleepwalking and nightmares, were among the least frequently reported sleep problems. Previous studies yielded conflicting data regarding the prevalence of parasomnias in autism. Patzold, Richdale & Tonge (1998) reported low levels of parasomnias among children with autism, while Schreck & Mulick (2004) noted increased incidence

of nightmares, sleepwalking, and bruxism. Our study seems to support a relatively low incidence of most parasomnias among children with autism. Head banging and crying during the night were also fairly low occurring events, another finding that runs contrary to intuition. It was also identified that sleep problems are not associated with problematic day time behaviours, parental stress and autism severity. However, autism severity showed a positive relationship with parental stress and problematic behaviours. Parental stress also showed a positive relationship with problematic behaviours in children. Hence, it can be concluded that there is a reported increase in parental stress with an increase in autism severity and problem behaviours in children with autism. It was also observed that problem behaviours are reported more in children with

more severe autism.

This study is an initial step in better understanding of sleep problems in children with autism. The study did not address issues such as severity and duration of sleep problems, nor was an attempt made to distinguish between sleep problems associated with autism and those associated with comorbid conditions. The study is limited by its subjective nature and possible bias in survey returns. We relied strictly on parent reports of sleep problems in their children. At least one study (Hering, Epstein, Elroy, Iancu, & Zelnik, 1999) has suggested that parent perception of sleep in children with autism may not always accurately reflect sleep patterns. Objective data in the form of actigraphic and polysomnographic studies are needed to better

delineate sleep architecture in this population, with efforts made to correlate objective and subjective sleep data. Only in this way, can sleep interventions be developed that meet the needs of children with autism and their families. Further research is also needed on the impact of sleep problems on academic performance in this population.

## Conclusion

Children and adolescents with autism are at substantial risk of experiencing sleep problems. The clinician assessing a child with autism should screen for sleep disorders and make appropriate referrals as indicated. Identifying and treating sleep disorders may result in improved sleep in children with autism.

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